

Policy and Practice Note / Note de politique et pratique

Cause, Care, Cure: Research Priorities for Alzheimer's Disease and Related Dementias*

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RÉSUMÉ

Une partie de la stratégie de l'Ontario sur la maladie d'Alzheimer et les démences connexes (MADC) était de développer les priorités de recherche et de recommander des stratégies pour le renforcement des capacités de recherche. Le processus adopté pour atteindre ces objectifs comprenait une analyse de l'environnement, des entretiens avec les informateurs clés, des enquêtes et un atelier de consensus ; ce processus a impliqué plus de 100 chercheurs, cliniciens, les personnes atteintes de démence précoce, et les aidants membres de familles. Ce document décrit le processus entrepris, les principaux problèmes identifiés et les recommandations pour les priorités de recherche et de renforcement des capacités de recherche ; il fournit également une orientation stratégique pour la recherche sur la démence en Ontario qui est pertinente pour d'autres juridictions. La recherche MADC dans tous ses aspects est nécessaire pour faire progresser la connaissance des causes de la démence, les soins et la guérison ; des lacunes existent actuellement dans la compréhension des approches efficaces pour les soins et le transfert des connaissances. La capacité pour la recherche de haut calibre reste sur le maintien de plans de carrière attractifs pour les chercheurs, des infrastructures solides et de partenariats forts. Afin que la recherche informera les politiques et pratiques, de meilleurs mécanismes seront nécessaires pour l'échange de connaissances.

ABSTRACT

Part of Ontario's strategy on Alzheimer's disease and related dementias (ADRD) was to develop research priorities and recommend strategies for building research capacity. The process to achieve these objectives included an environmental scan, key informant interviews, surveys, and a consensus workshop; this process involved over 100 researchers, clinicians, persons with early dementia, and family caregivers. This article describes the process undertaken, key issues identified, and recommendations for research priorities and for building research capacity; and provides a strategic direction for dementia research in Ontario that is relevant for other jurisdictions. ADRD research in all aspects is required to advance knowledge of ADRD cause, care, and cure; gaps currently exist in understanding effective approaches to care and knowledge transfer. Capacity for high-calibre research hinges on maintaining attractive career paths for researchers, solid infrastructures, and strong partnerships. For research to inform policy and practice, better mechanisms are needed for knowledge exchange.

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* This research-priority-setting initiative was funded by the Government of Ontario and managed by the Alzheimer Society of Ontario. We acknowledge Jenna Hollomby for her assistance with the planning and implementation of the consensus workshop. We are grateful for the contributions of all those individuals who participated in this priority setting process, and for guidance received from the members of the project Advisory Committee: Michael Borrie, University of Western Ontario; Larry W. Chambers, Élisabeth Bruyère Research Institute; Lorna de Wit, McMaster University; Sherry Dupuis, University of Waterloo; Nathan Herrmann, University of Toronto; Robert Hopkins, Kingston Psychiatric Hospital; Howard Mount, University of Toronto; Raymond Pong, Laurentian University; Parminder Raina, McMaster University; Nalini Rattan, Alzheimer Society of Canada; Ekaterina Rogaeva, University of Toronto; Jane Rylett, University of Western Ontario; Linda Stebbins, Alzheimer Society of Ontario; and Irene Turpie, McMaster University; and ex-officio members: Elizabeth Esteves, Ontario Seniors' Secretariat; Angie Szuch, Ontario Seniors' Secretariat; Eric Hong, Alzheimer Society of Ontario; Michael Klejman, Ontario Ministry of Health and Long-Term Care; and Caroline Lonsdale, Ontario Ministry of Health and Long-Term Care.

Manuscript received: / manuscrit reçu : 10/08/10

Manuscript accepted: / manuscrit accepté : 19/04/11

Mots clés : la maladie d'Alzheimer, la démence, priorité de recherche, capacité de recherche

Keywords: Alzheimer's disease, dementia, research priorities, research capacity

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Introduction

Alzheimer's disease and related dementias (ADRD) are progressive, degenerative illnesses affecting mental abilities, emotions, behaviour, and physical functioning (Patterson et al., 1999). They can create an overwhelming burden for family caregivers, negatively affecting their physical and mental health (Burton, Zdaniuk, Schultz, Jackson, & Hirsch, 2003; Peacock & Forbes, 2003; Schulz & Martire, 2004).

With the aging of the population, ADRD are expected to increase significantly in the coming years. In 2008, there were 103,700 new cases of ADRD in Canada; it is expected that this will increase by more than twofold in the next 30 years, with 257,800 new cases per year anticipated by 2038 (Alzheimer Society of Canada, 2010). This increase will be accompanied by an increased annual economic burden forecasted to be CAN\$153 billion (i.e., direct health costs, costs of informal caregivers, and indirect costs) in 2038, 10 times higher than in 2008 (Alzheimer Society of Canada).

The health care system is challenged to meet the needs of persons with ADRD (Callahan et al., 2006; Sachs, Shega, & Cox-Hayley, 2004), particularly due to limited recognition (Iliffe & Manthorpe, 2002; Valcour, Masaki, Curb, & Blanchette, 2000) and understanding of the disease (Boise, Camicioli, Morgan, Rose, & Congleton, 1999), limited access to specialty consultants, lack of community supports, and limited educational opportunities for health care providers (Teel, 2004). More research on diagnosis, management, and care is widely held to be crucial to advance care and support for persons with dementia and their caregivers (Chertkow, 2007; Lawton, 1996; Schölzel-Dorenbos, Meeuwssen, & Olde Rickert, 2010; Vellas, Reynish, & Robert, 2007).

Knowing that more research needs to be conducted is different from knowing which research should be carried out, or what processes can usefully set priorities. Consequently, the Ontario Seniors' Secretariat and the Ontario Ministry of Health and Long-Term Care partnered to develop and implement Ontario's five-year (1999–2004) strategy for ADRD (Ontario Ministry of Health and Long-Term Care, 1994). As part of the strategy, a research coalition was formed consisting of

researchers, the Alzheimer Society of Ontario (ASO), and community stakeholders. The coalition's strategic plan included a process to identify and recommend research priorities for ADRD based on needs, opportunities, capacities, and potential impact; and to identify and recommend priorities for building research capacity. The overall goal was to improve the quality of life for persons affected by ADRD and those who care for them.

A group of researchers, stakeholders, and community partners interested in ADRD formed a project advisory committee. The ASO managed this process on behalf of the Ontario government, and our group developed and implemented the project work plan.

This article summarizes the process implemented to identify research priorities for ADRD and provides a strategic direction for ADRD research, including recommendations for advancing research priorities, and enhancing and sustaining research capacity.

Methods

The project consisted of five components: (a) an environmental scan, (b) key-informant interviews, (c) focus group interviews, (d) quantitative surveys, and (e) a consensus workshop. The purpose of the environmental scan was to identify key ADRD researchers in Ontario, agencies and organizations funding ADRD research, current funding priorities, and potential partnerships (æstima research, 2004). Individual interviews were conducted with 15 key informants representing 11 key research funding bodies. These included the Canadian Institutes of Health Research (CIHR) Institutes of Aging, Neuroscience, Mental Health, and Addiction; the Natural Sciences and Engineering Research Council (NSERC); the Ontario Mental Health Foundation; the ASO; the Alzheimer Society of Canada (ASC); the Ontario Ministry of Health and Long-Term Care, and the National Institutes of Health – National Institute of Aging, Neuroscience and Neuropsychology of Aging Program (United States).

Specifically, informant interviews were conducted to explore: (a) research needs, (b) partnership opportunities for research funding, (c) capacity for excellent research and areas in need of increased capacity,

(d) impact of current resources devoted to ADRD research, and (e) optimal communication strategies to promote ADRD research and related opportunities (æstima research, 2005b). Key informant and focus group interviews were conducted with 11 researchers who were geographically representative as well as representative of CIHR's four pillars of health research (biomedical, clinical, health systems and services, population health); 16 clinicians (i.e., physicians, registered nurses, occupational therapists, social workers, physiotherapists, and psychogeriatric resource consultants) (Stolee et al., 2009); four persons with early stage dementia; and 23 family caregivers. Researchers were identified through a literature search and were included if they had published one or more papers related to ADRD in the previous five years, for which they were first author of at least one paper or if they had published four or more papers regardless of first authorships. Researchers were also selected to be representative across academic institutions. Clinicians were identified through Dementia Networks, Alzheimer Society of Ontario chapters, Regional Geriatric Programs, and clinical programs associated with academic Geriatric Medicine and Geriatric Psychiatry centres. Clinician interview participants were purposefully selected to be geographically representative as well as representative of major disciplinary perspectives. Persons with dementia and caregivers were recruited from support groups conducted by two chapters of the Alzheimer Society, one in a rural setting, the other an urban setting in Southwestern Ontario.

The interviews with researchers and clinicians included questions about new information needed ("What new knowledge do you think is needed to improve prevention, care, and treatment of ADRD?"); gaps in what we know and do about ADRD ("What do you think are the most important gaps in knowledge that research could address? In what areas do we lack good research evidence?"); existing research capacity ("In which areas do you consider Ontario's research community has the capacity to perform excellent research? In which areas should capacity be increased to perform excellent research?"); strategies to create unique research opportunities ("In what ways can Ontario create unique opportunities for research specific to ADRD?"); current funding opportunities (researcher interviews only; "Are you satisfied with current opportunities for research funding? Why is this? What initiatives do you think are necessary to improve or enhance funding opportunities?"); and possible impacts of putting more resources into research ("What do you think is the impact of current resources devoted to ADRD research, such as impacts related to advances in treatment, benefits to the health system and economic impacts?").

Persons with dementia and caregivers were asked questions related to new information needed to improve prevention, care, and treatment ("What do you think are the most important issues for researchers to study about Alzheimer Disease? Why?"); gaps in knowledge ("What questions do you have about ADRD that no one can answer for you? What do you wish we knew more about?"); the possible outcomes, or benefits, of putting more resources into research ("If more attention and money were spent on ADRD research, how would it help you/ your family member, and your community?"); and sources of information about ADRD ("How do you currently get information about ADRD, e.g., doctor, Alzheimer Society, websites, newsletters?").

The quantitative surveys were developed to expand knowledge and understanding of the issues raised by respondents in the environmental scan and key informant interviews, and to examine and confirm these themes with a larger sample (æstima research, 2005c). We used the results of the interviews – conducted as part of the environmental scan and with researchers, clinicians, persons with dementia, and caregivers – to develop the questionnaires. For example, all the specific areas identified as needing research were listed in the questionnaire, and respondents were asked to rate the importance of each research area; they were also given an opportunity to identify new topic areas. Questions were asked regarding: (a) the importance of further research in various areas of biomedical, clinical, health systems and services, population health, and psychosocial research; (b) research capacity and opportunities; (c) impacts of ADRD research; (d) funding opportunities; and (e) communication strategies. We scaled the questions using 10-point numerical rating scales (not at all important to extremely important) and 5-point Likert scales (agree–disagree). Opportunities were provided to acknowledge issues not previously identified.

We distributed the surveys to 187 researchers whom we had identified through the environmental scan and purposefully selected to be representative of the CIHR's model of four health research themes. Sixty researchers completed the survey (32% response); 31.0 per cent described themselves as conducting biomedical research, 55.0 per cent clinical research, 37.9 per cent health systems/services research, and 22.4 per cent health population research (percentages exceed 100% as researchers could select more than one theme). Surveys were also distributed to 246 clinicians, including physicians, nurses, social workers, physical therapists, occupational therapists, psychologists, and psychogeriatric resource consultants that we identified through a number of sources including Dementia Networks, ASO chapters, and Regional Geriatric Programs. A total of 106 clinicians completed the survey (43% response). Twenty-three

family caregivers and individuals with early dementia, who participated in the key informant interviews, also completed surveys to confirm their research priorities and to rate the importance of research priorities identified by the researchers and clinician groups.

We conducted the consensus workshop, which built on the preceding four components, on March 31 and April 1, 2005, in Toronto, Ontario (æstima research, 2005a). The four workshop objectives were to:

- (1) build on the emerging consensus of research priorities to identify a research focus that addresses both gaps and strengths;
- (2) generate recommendations to implement and sustain knowledge translation and communications strategies;
- (3) create strategies to foster cross-theme and other collaborative partnerships for research initiatives; and
- (4) identify actions required to develop and sustain research capacity, including a sustainable provincial research funding infrastructure.

In total, 53 invited participants attended the workshop. They included 17 researchers, 12 clinicians, 11 individuals engaged in both clinical and research activities, and 13 individuals representing policy and planning organizations including the Ontario Ministry of Health and Long-Term Care; Ontario Seniors' Secretariat; long-term care, mental health and seniors services associations; the Ontario College of Physicians; and the Alzheimer Society. The attendees took part in a facilitated consensus process that included pre-work (i.e., summary of prior work and preparatory questions) and a workshop involving presentations by invited speakers, small-group exercises, and larger group discussions (see Table 1). To determine how to best facilitate the process of identifying research priorities, we reviewed the proceedings of other consensus workshops related to the health care of older persons (Chambers et al., 2004; Hoenig & Siebens, 2004; Sidorenko & Walker, 2004; Solomon, LoCicero, & Rosenthal, 2004; Stolee, Borrie, Cooke, Hollomby, & the participants of the Canadian Consensus Workshop on Geriatric Rehabilitation, 2004). Consensus was defined as "what participants could support" rather than 100 per cent agreement.

Throughout this process, a number of principles were identified as guides for future development of research on ADRD:

- Develop a strategic plan that responds to the need for increased research capacity as well as the opportunities within the province, and that reflects cultural, ethnic, and geographic diversity.
- Invest strategically to support the internationally credible research already under way, as well as new areas of research and high-potential researchers.
- Maintain a balance of biomedical and psychosocial research, and of quantitative and qualitative research.
- Consider the full spectrum or continuum of health and social services for persons with dementia. Acknowledge

the needs of persons with dementia and their caregivers, and the impact of dementia on their quality of life.

- Encourage inclusivity – active involvement/collaboration/partnerships between researchers, clinicians, persons with dementia, and family caregivers.
- Emphasize knowledge exchange.
- Create and capitalize on opportunities for increased funding and knowledge exchange.
- Make the most of opportunities for cross-theme collaborations and partnerships to identify relevant and critical research priorities, to build research capacity, and to stimulate knowledge exchange and translation.

Results: Consensus Statement on Research Priorities

Table 2 presents the list of research priorities, related to the cause, care, and cure of ADRD, generated through the consensus process. Many of the topics are consistent with those identified in a 2002 national workshop that explored research directions for caregiving in Alzheimer's disease. At both workshops, topics such as recognizing both the positive and negative impacts associated with caregiving, developing, and evaluating interventions for caregivers, and research methodologies were identified (Chambers et al., 2004).

Recommendations for Action

The workshop consensus process led to recommendations within three strategic directions:

- (1) Advancing research
- (2) Building capacity
- (3) Linking research with policy and practice

Many of these recommendations are inter-related and inter-independent.

Call to Action: Advance Research

Research in all aspects of ADRD is required to advance knowledge of cause, care and cure; and there are gaps in applying what is already known about ADRD and about effective approaches to care.

Rationale for Action

- Although a great deal is known about ADRD, there is still much to discover in all areas. The *cause* of ADRD is unknown, but is associated with aging, and likely involves many genetic and environmental factors; there is no known *cure* for ADRD; and while research aimed at cause and cure for dementia is of utmost importance, the current *care* needs of those with dementia highlight the urgent need for clinical, health services and psychosocial research.
- It is important to build on existing research strengths, including centres that conduct biomedical research (genetics,

Table 1: Workshop strategy**PREWORK**

Participants received summary of the information gathered to date on this project. In preparation for the workshop participants were provided with key questions to consider:

- Based on the information you read, how would you interpret areas of research strength and research gaps in Ontario?
- What ideas do you have about collaborative/cross-theme research initiatives in the following broad theme areas – cause, care, cure?
- What advice do you have about Knowledge Exchange strategies that will help bridge the gap between clinicians, researchers, policy makers, people with dementia and their caregivers, and other stakeholders?
- What recommendations do you have to facilitate best-practice information sharing in urban and rural settings?
- What ideas do you have about how to create a sustainable infrastructure for research in Ontario? What might this infrastructure look like?
- What is required to build the capacity of people who will be/are involved in ADRD research? Please think about students, emerging and experienced researchers, and clinicians.
- What are your top 3–5 recommendations to enhance Ontario’s research in the field of ADRD?

WORKSHOP PROCESS

Presentations: For each of five topic areas, there was either a review of information gathered to date or a presentation from an invited speaker.* These areas were as follows:

- I. Research Strengths and Gaps
- II. Research Priorities
- III. Cross-theme and Collaborative Partnership Opportunities
- IV. Knowledge Exchange
- V. Research Capacity and Sustainable Infrastructure

Small-Group Activities: Participants completed small-group exercises designed to stimulate discussion and develop key recommendations in each topic area; results of the exercise were presented back to the larger group. Participants were then asked to record 3–5 top research priorities, and 3–5 key recommendations, regarding research capacity and overall research principles.

Large-Group Calls for Endorsement: Following each of the small-group activities, larger group discussions provided an opportunity to determine consensus with calls for endorsement of identified research priorities.

*** Invited speakers were: Dr. Jack Diamond, Scientific Director, Alzheimer Society of Canada; Dr. Kenneth Rockwood, Institute Advisory Board of the Canadian Institute of Health Research, Institute of Aging, Professor of Geriatric Medicine and Neurology, Dalhousie University; and Dr. David Davis, Professor, Faculty of Medicine, University of Toronto. The workshop opened with remarks from Linda Stebbins, Executive Director, Alzheimer Society of Ontario, and the Honourable John Gerretson, Minister Responsible for Seniors.**

biomarkers, pathophysiological mechanisms), pharmacokinetic and pharmacological research aimed at a cure, caregiver research, clinical trials, and research that promotes knowledge exchange.

- It is necessary to examine the nature of cognitive decline, of which dementia is one consequence.
- There is a need for better knowledge exchange to make the most of what is already known about ADRD and effective approaches to care, and support more rapid application of new research findings.
- There is a need to recruit and retain high calibre research personnel.

There are still many unknowns about dementia across all areas of research, as reflected in the following comments from the interview participants:

There’s a heck of a lot of progress that’s been made in the last ten years so we know a lot more than we did 10 or 20 years ago, certainly a lot more than 40 years ago, so I think we’re making progress, but we’re still not there, we haven’t cracked this disease. [Researcher]

I’m still struggling with the amount of knowledge that is out there that is both confusing and conflicting. If you look at prevention, every week or every so often there’s a new research article on – you know, whether it’s one or two hours of walking every day, exercise and ginkgo biloba and vitamin E, and then red wine ... Is there a simple message like they used to have for heart or cancer? Maybe a meta-analysis of the existing data of both prevention and also how practically helpful some of the medications are. [Clinician]

Persons with dementia and family caregivers commented on the need for more information on causes, earlier diagnosis, and understanding the stigma associated with dementia, as reflected in the following comments:

Why me?
[Person with Dementia]

We went to the doctor in 1994 and said we knew something wasn’t right. But she wasn’t diagnosed until 1998. There has to be a better way to figure

Table 2: Consensus statement on research priorities

Cause	<ul style="list-style-type: none"> • Understanding the physiological and molecular mechanisms of dementia • Identification of risk factors (environmental and genetic)
Care	<ul style="list-style-type: none"> • Early diagnosis <ul style="list-style-type: none"> ○ Development of early diagnostic tools and markers ○ Mild cognitive impairment: Assessment and interventions • Impact on persons with dementia and family caregivers <ul style="list-style-type: none"> ○ Impact on quality of life of persons with dementia ○ Impact of the caregiving role: stress, support needs, and quality of life for families and caregiving units ○ Understanding the caregiver role ○ Critical appraisal and synthesis of caregiving research to provide direction ○ Education of those at the “periphery” of care and the community at large to enhance understanding and address stigma and stereotypes • Better care options <ul style="list-style-type: none"> ○ Health promotion for those with dementia ○ Home care, including the impact of current funding ○ Long-term care, including evaluation of care, reduced wait times, and alternative options to long-term care placement ○ Role and impact of other services, including respite care, family support services, and dementia units ○ Care and service issues, including transitions between services, staffing ratios, and standards of care ○ Technologies and technological support for persons with dementia ○ Clinically relevant outcome measures, and research to identify these measures
Cure	<ul style="list-style-type: none"> • Cure for Alzheimer’s disease and related dementias • Effective treatments, including drug interventions (with minimal side effects) and non-drug interventions: <ul style="list-style-type: none"> ○ At different stages of dementia ○ For dementia subtypes

this out. We knew something was wrong but the doctor kept saying everything was fine ... They have to figure out how to do this earlier Doctors need to learn how to do this. [Caregiver]

Why do people hide it? How can we help them to come out and talk about it? [Person with Dementia]

Recommendations

The process consensus resulted in five recommendations, listed here:

- Endorse the research priorities related to the *cause, care, and cure* of ADRD identified in this research priority setting initiative (see Table 3), and use these priorities as a basis for articulating detailed research questions.
- Use research methodologies that maximize research potential, for example, longer-term studies, qualitative methodologies (e.g., phenomenology, grounded theory, case study), meta-analyses and systematic reviews. Funding bodies need to acknowledge and support these methods.
- Encourage more interdisciplinary research, partnerships, and collaborations to advance the identified ADRD research priorities and to leverage both intellectual and physical resources.
- Conduct more research to learn which knowledge exchange activities are most effective to link research, care and support, and policy.
- Build on existing centres conducting dementia related research.

Call to Action: Build Capacity

The potential to conduct high-calibre research hinges on maintaining attractive career paths for emerging and established research personnel, a solid infrastructure, and strong partnerships.

Rationale for Action

- An investment in capacity building strategies will advance research in Ontario and elsewhere. The following challenges limit achieving full potential:
 - Infrastructure: lack of support for research support staff, interdisciplinary teams, labs, and other resources (brain tissue and research participants).
 - Projects: few opportunities or specific venues for funding ADRD research.
 - People: There is a danger of not having enough experienced researchers who specialize in this field and who will mentor new researchers.
- There are opportunities to coordinate efforts of funding agencies and to leverage national funding agencies to increase capacity for ADRD research.

The majority of researchers interviewed indicated that Ontario has the capacity to perform state-of-the-art, internationally renowned research across various themes. However, many researchers highlighted concerns about the province’s ability to maintain this capacity given

Table 3: The percentage of survey respondents (total sample, researcher sample, clinician sample) that agreed* with the listed strategies to increase research capacity and opportunities

Strategies to Increase Research Capacity and Opportunities	All Respondents (n)	Researchers (n)	Clinicians (n)
Greater number of grants and greater financial support	89% (161)	91% (58)	87% (103)
Provincial government funding for Ontario-specific research (e.g., service delivery)	88% (162)	80% (58)	90% (104)
More opportunities for fellowships and studentships to establish ADRD researchers early in their careers	88% (162)	90% (58)	86% (104)
Better strategies to attract new and retain existing researchers	88% (160)	84% (58)	90% (102)
Create ADRD research institutes that focus on both biomedical and psychosocial aspects of dementia	80% (162)	67% (58)	87% (104)
Develop a network focusing on the dissemination (exchange) of new knowledge	77% (162)	63% (57)	85% (105)
Increased funding and involvement in research initiatives from the Alzheimer Society	76% (162)	80% (58)	74% (104)
Create multi-centre research partnerships	75% (163)	66% (57)	80% (105)
Development of formal mechanisms to bring dementia researchers together	73% (163)	66% (58)	77% (105)
A provincial research foundation for health care (like the Alberta Heritage Foundation)	72% (163)	83% (58)	66% (105)
Models for multi-disciplinary research	72% (159)	80% (56)	77% (103)
Development of a coalition or network of ADRD researchers	70% (164)	61% (59)	75% (105)
Better and more imaging equipment	57% (161)	46% (59)	64% (102)
Revision of criteria for evaluating proposals that include clinicians and community groups as investigators because traditional criteria (e.g., number of publications) are not applicable	57% (160)	43% (58)	65% (102)
Coordination of research participants through Alzheimer Society – increase access to research participants	55% (161)	54% (57)	56% (104)
Better resourced and organized Brain Bank – increase access to brain tissue	48% (161)	47% (58)	50% (103)

* Ratings of "agree" or "strongly agree" on the 1–5 scale; 1 = strongly disagree, 3 = neutral, 5 = strongly agree

limited resources (primarily funding) and emphasized the need for initiatives to develop and sustain research capacity, as reflected in the following comments:

I think we have the capacity to perform excellent research at almost every level, right from genetic molecular (including mechanisms of disease), on up to psychosocial functions. But there's lack of a support system for younger and mid-career individuals to maintain and sustain that. [Researcher–10]

We have no research system. It's like a crap shoot, if you want to do research. Well, be prepared to be miserable for at least the first 5–10 years, and if you're lucky enough to be successful nationally in your first application, you just might be able to hang on. Otherwise, good luck. [Researcher–12]

Building on information collected in the environmental scan, survey respondents were presented with a list of potential strategies and opportunities for building dementia research capacity and asked to rate the extent to which they agreed or disagreed (5-point scale: strongly disagree, disagree, neutral, agree, strongly agree) with each statement. Overall, the majority of respondents agreed or strongly agreed with the listed strategies to increase research capacity and opportunities, with the exception that only 48 per cent

agreed with the need for a better resourced and organized brain bank (see Table 3). A high percentage of respondents (greater than 88%) agreed with the need for greater financial support, particularly for students, as well as increased provincial government funding and better strategies to attract and retain researchers. Generally, there was much agreement between researchers and clinicians, although there were some differences between these groups on their perceptions of the need for a provincial research foundation for health care, better and more imaging equipment, the development of a network focusing on the exchange of new knowledge, and the creation of multi-centre research partnerships.

Recommendations

The consensus process generated six recommendations in the area of building capacity:

- Create career development programs that include trainee programs, fellowships, and chairs to attract and retain researchers in this field.
- Create opportunities for new and established researchers to investigate new and innovative lines of research.
- Implement programs to recruit and retain research support staff (research assistants and associates) and technical staff.

- Strengthen partnerships among key stakeholders to facilitate all aspects of research including coordination with funding sources, access to research resources, and knowledge exchange.
- Explore how the Alzheimer Knowledge Exchange (AKE; www.akeontario.org) can support infrastructure requirements of space, equipment, and resources, and facilitate communication with funding agencies. The AKE is a vehicle for linking people, resources, and ideas related to ADRD and is part of Ontario's Seniors Health Research Transfer Network (SHRTN; www.shrtn.on.ca) collaborative, along with the Ontario Research Coalition (Chambers, Luesby, Brookman, Harris, & Lusk, 2010).
- Investigate opportunities to form a research foundation with a focus on collaboration and connecting initiatives.

Call to Action: Link Research with Practice and Policy

For research to inform policy and change the way care is provided for persons with dementia, better mechanisms are needed to exchange knowledge and information among persons with dementia, caregivers, policy-makers, clinicians, and researchers.

Rationale for Action

- In general, research is not being used adequately to inform policy or change practice to improve the care of persons with dementia.
- There is a need for increased understanding of the educational, training, and information needs of persons with dementia, caregivers, policy makers, clinicians, and researchers, and a need for these groups to have better access to research findings. Unfortunately, it is often difficult for those who need research information to access and apply it.
- There is a need to share information within and between these groups.
- Each of these groups requires different types of information and various vehicles to deliver messages in meaningful ways.

Knowledge exchange activities are a mechanism in which recommendations for advancing ADRD research and building capacity can be achieved. Researchers, clinicians, and funding body representatives described challenges associated with minimal collaboration between those who do research and those in a position to apply it to health care practice. Opportunities for information sharing and knowledge exchange were identified as strategies for overcoming these challenges, as reflected in the following comments:

Again, I come back to that loop ... where research is informed by practice as well as research informing practice ... So I think the people who are doing the research need to be in more regular communication with people that are going to be applying

the outcomes of research. They need to be in connection with the people who are identifying huge gaps and needs; they need someone to help them identify what people's needs are. [Funding body representative]

What we've seen in the past of the academics running these gorgeous, gorgeous programs that have been designed in a very, very clean way [is that] those kinds of programs just don't generalize when you go out to the community and run [them], so I'm sort of saying (a) let's have more intervention programs that we're trying, and (b) let those programs originate in the community rather than in academia. [Researcher]

There is a little bit of knowledge on the street in terms of some drugs now that might slow down the development or the progression of Alzheimer's for a year or two. But I still say it's [Alzheimer's disease] not that well-known out on the street, and there's possibly a lot more that could be done. [Clinician]

Persons with dementia and family caregivers commented that the Alzheimer Society was their major source of information about dementia because health professionals were often unable to answer their questions either because of lack of information or time.

I don't know how those not connected [to an AS chapter] get information because no one knows as much as [they do], or has all the information like the pamphlets they give out about what it is and what you can do. [Person with dementia]

Recommendations

Four recommendations were made:

- Enhance the role of the AKE to take the lead to
 - advance ADRD research, and
 - bring together the research and clinician communities.
- Capitalize on existing evidence about knowledge exchange to further enhance knowledge transfer to practice and to encourage interactions between clinicians and researchers.
- Foster the Alzheimer Society's advocacy role to
 - endorse the AKE;
 - take this Call to Action to key partners; and
 - engage funding partners and other organizations interested in working collaboratively to move this research initiative forward.
- Coalesce with the government-supported SHRTN initiative and other opportunities for knowledge exchange to leverage the impact of research on meeting health needs of seniors, including those associated with ADRD.

Potential Strategies to Advance this Initiative

Throughout the overall process, a number of strategies were identified to encourage collaborative research,

knowledge exchange, and to increase funding opportunities for ADRD research and career support.

Strategies to Encourage Collaborative Research

Seven strategies were formulated to encourage collaborative research:

- Encourage multi-centre partnerships with the development of Regional Centres of Excellence to integrate researchers, clinicians, and students into a multidisciplinary approach.
- Develop incentives (e.g., stipends, release time) for clinicians to participate in multi-centre, multi-disciplinary, cross-theme, collaborative research and act as mentors to other clinicians and researchers. The development of these kinds of incentives will increase research opportunities and capacity, and also contribute to a cultural shift that values and prioritizes ADRD as a research, clinical, and societal priority.
- Endorse initiatives and resources that support clinician collaboration in research (e.g., electronic health records, AKE).
- Support training and mentorship strategies that promote collaborative research initiatives; collaborative networks of researchers and clinicians; and initiatives that encourage multi-centre and multi-disciplinary partnerships.
- Foster, in workplace settings across health sectors, a research culture that values investing in research and collaborative partnerships. Develop and implement strategies to increase awareness of the importance of research.
- Revise the criteria for evaluating funding proposals to be more clinician-friendly (i.e., reduced emphasis on number of publications, academic training) since the capacity of clinicians to participate in collaborative research is currently compromised by funding agency criteria that are not appropriate or consistent with clinicians' work.
- Lessen the emphasis on competitive funding models and heighten incentives to develop collaborative partnerships for research.

Strategies to Encourage Knowledge Exchange

Five top-level strategies were formulated for knowledge exchange:

- Organize regular knowledge exchange forums for researchers, funding agencies, clients, and providers to identify themselves, share information, generate ideas/questions, and form alliances and partnerships.
- Endorse knowledge exchange strategies that are consumer-driven, relevant, readily accessed ("3 clicks, 30 seconds"), and easily understood.
- Capitalize on existing knowledge exchange strategies including:
 - the use of technology (Web-based forums, interactive media such as E-Learning; videoconferencing);
 - a virtual network;
 - partnerships between rural and urban initiatives;

- engagement of partners such as architects about the design of environments; and
- multiple and innovative methodologies (story-telling, drama, problem-based, and just-in-time learning opportunities).
- Consider the role that existing resources, such as psycho-geriatric resource consultants, Alzheimer Society educators, Dementia Networks, and other education programs, can play in knowledge translation.
- Require research proposals to have a well-developed dissemination and knowledge exchange plan.

Strategies for Increasing Funding for ADRD Research and Career Support

Three strategies were identified in the funding area.

- Establish new provincial funding structures to build and sustain research capacity by providing career support, program-based and project-specific funding, and infrastructure support. Potential models for an Ontario-based research foundation include Alberta Innovates (formerly the Alberta Heritage Foundation), the British Columbia Michael Smith Foundation, and the Nova Scotia Health Research Foundation.
- Build an ADRD research institute. Potential models include the Rick Hansen Spinal Cord Injury Network and the International Spinal Cord Injury Research Centre, both of which are located in British Columbia.
- Develop partnerships for funding research, including partnerships with government, national funding agencies and industry, including drug companies, technology and biotechnology companies, and banks. Partnerships with industry provide valuable opportunities for collaborating on research towards a cure; often, only industry has the money needed to provide large enough sample sizes to adhere with evidence-based guidelines. Industrial partnership is also typically essential for developing assistive technologies including intelligent devices and living environments to support individuals with cognitive impairment.

Strategies to Increase Access to Research Resources

Two strategies were developed for this goal:

- Refurbish the existing Brain Bank.
- Set up a Registry of Caregivers and a Registry of Persons with dementia (Alzheimer Registry). The AS, with regional chapters and resources, could be in a position to develop and maintain these registries.

Discussion

This five-part initiative identified ADRD research priorities and strategies to enhance research efforts to increase knowledge about the cause, and cure of ADRD, and to improve care and support for those with dementia and their caregivers. Many of the strategies for building research capacity are consistent with those highlighted for increasing capacity for research on caregiving in Alzheimer's disease (Chambers et al., 2004).

Strengths of our priority-setting process include its comprehensive approach to gathering relevant input from all stakeholders, including persons with dementia and their caregivers; the use of multiple methods, including an environmental scan, key informant and focus group interviews, and quantitative surveys; and a face-to-face consensus workshop guided by results from all prior phases.

Although this priority-setting initiative was undertaken in 2005, the priorities and directions identified continue to be relevant and can inform other initiatives aimed at supporting research capacity, and knowledge translation and exchange, in dementia. Several recent initiatives reinforce the relevance of this work. The *Rising Tide* report released by the ASC (Alzheimer Society of Canada, 2010) highlights the population and health system impact of dementia. The ASC recommended the development of a National Strategy for ADRD acknowledging the importance of investment in research to support improvements in diagnosis, management and prevention, and in all areas of research including biomedical, clinical, quality of life, health services, and knowledge translation. At a minimum it was recommended that Canada triple its dementia research expenditures beyond the CAN\$24 million currently being invested by CIHR and the Alzheimer Society (Alzheimer Society of Canada, 2010). Increased commitments to research are also advocated in proposals (with involvement of the Alzheimer Society) for provincial (Ontario Neurological Joint Working Group, 2010) and national (Neurological Health Charities Canada, 2010) brain strategies. Note that while development of national strategies may be complicated by Canada's federal system, with provincial responsibility for health care delivery (Rockwood & Keren, 2010), the federal government's role in research funding is not similarly constrained. There is a tremendous opportunity to strengthen the position of ADRD research in a highly competitive funding environment. Investing in an integrated communications strategy is required to sustain interest and enthusiasm in ADRD research priorities, funding, capacity-building, and knowledge exchange.

A common theme arising throughout this consensus process was the need for easy access to existing ADRD-related research and for opportunities for knowledge exchange across all key stakeholder groups. The newly developed CIHR-funded Canadian Dementia Knowledge Translation Network (www.lifeandminds.ca) is a major initiative that is building on this research-priority-setting process and helping to realize the recommended research capacity building and knowledge exchange strategies, particularly through its Canadian Dementia Resource and Knowledge Exchange (www.dementiaknowledgebroker.ca). This network provides

a national vehicle that builds on work of groups such as Ontario's AKE and SHRTN to support research and knowledge exchange activities that can inform dementia practice and policy, and benefit dementia patients and their caregivers.

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